

***NEW
FAMILY SUPPORT
GUIDELINES &
PROCEDURES***

DEPARTMENT
OF
MENTAL RETARDATION
Commonwealth of Massachusetts

July 2002

**Massachusetts Department of Mental Retardation
FAMILY SUPPORT GUIDELINES & PROCEDURES**

TABLE OF CONTENTS

INTRODUCTION	3
GLOSSARY OF TERMS	4
I. GUIDING PRINCIPLES OF FAMILY SUPPORT	7
II. CORE ELEMENTS OF FAMILY SUPPORT	8
III. FAMILY SUPPORT SERVICES	9
IV. ALLOWABLE/ DISALLOWABLE EXPENDITURES	13
V. FAMILY-GOVERNED, ENHANCED SERVICES & SPECIALTY PROJECTS	18
VI. DETERMINING ELIGIBILITY FOR FAMILY SUPPORTS	19
VII. PRIORITIZATION, ALLOCATION OF RESOURCES AND APPLICANT TRACKING PROCESS	22
VIII. DEVELOPMENT OF FAMILY SUPPORT PLAN	25
IX. ADMINISTRATIVE RESPONSIBILITIES OF FAMILY SUPPORT PROVIDER AGENCIES	27
X. GOALS AND PERFORMANCE OBJECTIVES	31
XI. EVALUATIONS	31
XII. ATTACHMENTS	32
A- Family Support Plan {Draft}	
B- Family Support Allocation Guidelines	
C- Transfer of DMR Family Support Funding	
D- Letter Confirming Change in Responsible Local DMR Area Office	
E- Performance Outcome Measures	
F- Vehicle/Home Modification Funding Request Form	
G- Vehicle Modification or Lease/Purchase Guidance	
H- Home Modification Guidance	

Massachusetts Department of Mental Retardation

FAMILY SUPPORT GUIDELINES & PROCEDURES

INTRODUCTION:

We are pleased to provide you with a copy of our new *Family Support Guidelines and Procedures*, which will become effective July 2002. This document has been designed for a variety of audiences: families, Family Support Provider Agencies, and DMR staff. We encourage families, Family Support Provider Agencies and the Department staff to familiarize themselves with the content. We have incorporated both a conceptual framework for the design and implementation of a broad array of family supports, as well as specific technical details about the operational requirements. It is our expectation that all parties will adhere to the technical and operational requirements and standards set forth in these *Guidelines and Procedures*. This is essential for the successful implementation of our family support system. It is our commitment and expectation that these *Guidelines and Procedures* will continue to provide families flexibility and choices that enable them to support their family member with a disability at home and in their community.

GLOSSARY OF TERMS

ADULT- Individual who is 18 years of age or older.

AGENCY PAID STAFF AND SUPPORT WORKERS- Family support worker who has been hired by the agency and is on the agency payroll. This includes respite workers.

AREA DIRECTOR (AD)- A person who oversees the administration of services and supports for those eligible individuals and families tied to that area office based on the defined catchment areas.

AREA OFFICE (AO)- Locally based DMR offices (24 statewide) responsible for the organization, coordination, and provision of services or supports to individuals and or families whose area of service falls within that office's geographical scope.

BROKER- Provides assistance to a family to identify and plan supports, to access services and supports, or to evaluate the usefulness of the supports they have identified in their family support plan.

CASE MANAGEMENT- Active relationship with individuals and families to provide support, guidance, problem-solving and assistance in accessing a range of supports such as inclusive community activities, and educational and generic community resources (day care, health benefits, medical supports, etc.)

CHILD- An individual who is younger than 18 years of age.

CONSUMER REGISTRY SYSTEM (CRS)- The internal information database system for DMR that tracks past and current service information on individuals who are known to the DMR service system. Type of information entered: Social Security #, name, DOB, address, area of tie, date of eligibility, diagnosis, etc.

CRIMINAL OFFENDER RECORDS INFORMATION (CORI)- This is information regulated by the Criminal History Systems Board and maintained by the Board of Probation regarding the criminal histories of persons within the Massachusetts Court system.

DIRECT PROVIDER AGENCY PAYMENT- In the use of flexible family support the provider agency manages the family allocation and pays for the support, goods and services on behalf of the family.

FAMILY- Parents, foster parents, spouses, siblings, and others who perform the roles and functions of family members in the life of an individual, including persons in a relationship of mutual support with an individual that is exclusive and expected to endure over time.

FAMILY ADVISORY COUNCIL- A group of persons that consists primarily of family members that advises the Family Support Provider Agency on the planning, implementation, and evaluation of services and supports.

FAMILY DIRECTED PROJECTS- Family support initiatives in which families are fully involved in guiding the manner in which supports are offered for each particular family support project. DMR and Family Support Provider Agencies maintain the governance of the project.

FAMILY GOVERNED PROJECTS- Families exercise control over major operational decisions including hiring/firing staff, managing the budget, development of policies and procedures, etc. Family governance allows family groups to determine their membership from an identified group of eligible individuals and to prioritize and allocate family support funds for individuals.

FAMILY IDENTIFIED STAFF- Family independently recruits and hires self-identified staff for support (respite, skills training, etc.).

FAMILY SUPPORT- A DMR support service model for families who care for their family member with a disability at home. Family Support is designed to provide a wide array of options to families of individuals with disabilities that enable them to stay together and to be welcomed, contributing members of their home communities.

FAMILY SUPPORT AGENCY/FAMILY SUPPORT PROVIDER AGENCY (FSPA) – Agency with day-to-day responsibility for the operation of services or supports regulated by the Department by law or contract.

FAMILY SUPPORT ALLOCATION- Allocation refers to the amount of dollars made available to a family based on completion of a needs assessment, availability of resources and their identified prioritization for funding as determined by the Area Director. The allocation is inclusive of other service costs such as case management, etc., as well as flexible allocation. This allocation is managed either by the Family Support Provider Agency (Direct Provider Agency Payment) or by the family (Stipend).

FAMILY SUPPORT FUNDS- Refers to the dollars used to implement the Family Support Program

FAMILY SUPPORT PLAN (FSP) – Provides a listing of supports, goods, and services that have been identified to be appropriate to meet the needs of the family during the existing fiscal year as well as the associated cost to DMR. The Support Plan is signed by the designated provider agency staff, family member, and, when appropriate, the individual.

FAMILY SUPPORT STAFF/STAFF MEMBER- Provider agency staff who is funded by a DMR family support contract whose role is other than 1:1 direct service, i.e., case manager, supervisor of family support, etc.

FLEXIBLE FUNDING - A component of the Family Support model that provides funds to families to be used in a flexible manner in the purchase of goods and services to support their family member with a disability in their home and community. This includes both stipends and direct provider agency payments.

GENERIC SERVICES- Services, supports, or treatment options generally available to the population-at-large with or without special accommodations.

HOME COMMUNITY BASED WAIVER (HCBS)- A federal program authorized by Section 1915 (c) of the Social Security Act. The waiver is a Medicaid program that provides home and community based services to individuals, who but for the provision of such services, would require the services of an Intermediate Care Facility. Individuals who are eligible for DMR services and Medicaid and who meet level of care requirements, may be enrolled in the Massachusetts waiver program and receive an array of community based support services.

INDIVIDUAL- A person receiving services or supports provided, purchased, or arranged by the Department.

INDIVIDUAL SUPPORT PLAN (ISP) – A written plan of services or supports for an individual over the age of 22 which is developed, implemented, reviewed, and modified according to the requirements of the Department's regulations on individual support plans.

REGIONAL DIRECTOR (RD)- A person who oversees the administration and management of supports to those area offices within the region's catchment area. DMR has 5 defined regions; Western, Central, Northeast, Southeast, and Metro.

REGIONAL FAMILY SUPPORT DIRECTOR/REGIONAL DIRECTOR OF FAMILY SUPPORT- Person who provides direction, oversight, and support for the planning and delivery of Family Support Services provided within that DMR Region.

REGIONAL OFFICE- Location within the DMR region where DMR staff implement the policies and standardization of those services provided within that region's area offices.

RESPIRE- A period of rest or relief provided for the family in the care and supervision of their family member with a disability.

SCHOOL DISTRICT- The municipal city, town or regional school district that has the programmatic and financial responsibility in which the student resides.

SERVICE COORDINATOR- Person designated by the Department to arrange, coordinate, or monitor, or to remain informed about, services or supports provided, purchased, or arranged by the Department for a particular individual.

SERVICES- A system of formalized supports, generic or specialized.

STIPEND- Family Support Provider Agency makes a payment directly to the individual or family, who then pays directly for goods and services.

SUPPORTS- Resources and strategies that promote the interests and causes of individuals with or without disabilities; that enable them to access resources, information, and relationships inherent in integrated environments and that result in their enhanced independence, productivity, community integration and satisfaction.

Massachusetts Department of Mental Retardation

FAMILY SUPPORT GUIDELINES & PROCEDURES

I. GUIDING PRINCIPLES OF FAMILY SUPPORT

The primary goal of family support is to provide a wide array of options to families of people with disabilities that enable them to stay together and to be welcomed, contributing members in their home communities. Individuals belong with and do best with supportive families. All individuals should be able to live in a safe, permanent, stable, and nurturing family relationship in a family home. Families, therefore, should have access to supports that are necessary, desirable, and appropriate to prevent unnecessary separation of their disabled family member from their family.

Families are experts regarding their strengths, competencies, capacities, and needs of their family members and are in the best position to know what will help them provide for a family member with a disability. Family support is based on respect for families and recognition of their expertise, their diversity, unique characteristics, and their cultural and spiritual values.

Individuals with disabilities and their families can enrich the lives of others in many ways. Family support promotes the development and growth of relationships and natural support networks within the context of community living. It encourages families in their efforts to promote the inclusion of their family members with disabilities in education, recreation, and all other aspects of community life.

People with disabilities have personal preferences and needs to live, learn, grow, and have relationships. They have abilities, competencies, and dreams, and should be supported and encouraged to pursue their personal desires. Family support responds to family-identified needs and direct input from individuals with disabilities. It offers them the opportunity to exercise control and direction over the supports that are available to them.

A. Family support strives to achieve the goal of helping families stay together through:

- developing the family's natural capacity to meet the needs of family members;
- offering additional supports such as staff resources, goods and services, and financial assistance; and
- enhancing the capacity of communities to value and support people with disabilities and their families.

B. Operating principles that guide family support activities are:

- Individuals with disabilities and their families are recognized as primary decision-makers about their lives and supports.
- Family support focuses on the whole family and recognizes that benefits to the whole family also benefit the person with a disability.
- Family support requires flexible options that are responsive to families' unique needs, strengths, and cultural values.
- Families are afforded opportunities for increasing control in the planning, implementation, management, and evaluation of satisfaction of family support services.
- Families are encouraged and supported to develop their natural capacities for innovation, initiative, and leadership.
- Family support operates in ways that respect individuals with disabilities and their families as valued members of their communities.

- Family support should be equitably and fairly available throughout the state.
- Family support is pro-active and encourages family independence and capacity-building.
- Family support builds on existing natural and community supports and maximizes the use of generic resources.

II. CORE ELEMENTS OF FAMILY SUPPORT

The DMR Family Support program is based on the principle that individuals and families know their own needs. For this reason, and because of the individuality of each family, the range of goods and services available under the program is very broad. This approach allows families the flexibility to identify the resources that will be helpful to support their family member in his/her home. Families are always encouraged to identify resources within their community that can offer assistance.

Family Support Provider Agencies shall offer specific services from which families may choose based on the availability of funding and subject to appropriation. These services shall be responsive to the dynamic and changing needs of the family and of the individual with a disability throughout his/her respective stages in life.

Families may expect that Family Support Provider Agencies will do the following:

1. Respond to the specific ethnic, cultural, and linguistic needs of families in the geographic area that they serve.
2. Offer timely and relevant information to families regarding available resources in the community. This may include various private/public resources, brochures, newsletters, WEB pages, library collections, and other community connections.
3. Arrange for or provide a variety of support services for families including information and referral, support groups, educational forums, training sessions, and fostering parent-to-parent connections and networks.
4. Engage individuals and families in the family support planning process and assist them to identify their strengths, needs, other resources available to provide assistance, as well as an individualized family emergency contingency protocol.
5. Develop partnerships, and identify and engage in collaborative activities with other Family Support Provider Agencies and community organizations to access resources and services. Examples of such activities include joint sponsorship of sibling support groups and family education programs.
6. Support and empower families to develop their leadership skills and to assume leadership roles, e.g., participation in family-directed projects.
7. Provide the stipend option to families in their array of services, based on the family's needs and preferences identified in the family support plan.
8. Provide case management services for families. Case management requires Family Support Provider Agencies to maintain active relationships with families and to offer support, guidance, and engage in problem solving as needed.

9. Provide or arrange for agency-paid staff and support workers for planned in-home and out-of-home services including respite, skill building and recreational activities.
10. Assist families to identify, and/or hire and train respite staff/support workers.

III. FAMILY SUPPORT SERVICES

A. FAMILY LEADERSHIP AND DEVELOPMENT

Family supports should encourage individuals and families to develop their natural capabilities for innovation, initiative, and leadership. Family support projects will be family-governed, directed, and managed in accordance with families' preferences and needs. It is recognized that some families may need to relinquish their leadership roles from time to time but should be re-invited when ready. Family Support Provider Agencies will encourage and support families in attending family leadership training and other events that strengthen the capacity of families to advocate for and to obtain what they need.

B. FAMILY ORIENTATION, EDUCATION, AND TRAINING

1. In order to inform families about the various support options available to them, the Family Support Provider Agency, in conjunction with the DMR Area or Regional Office, will conduct a series of informational meetings for families throughout the fiscal year. The DMR Regional and Area Office staff and Family Support Provider Agency staff shall provide families and individuals with information that describes DMR's role in family supports, the location of the local Area Office, and the names of key Area and Regional Office staff who can be contacted for additional information or problem solving.
2. Family Support Provider Agencies shall provide information and materials in a variety of formats that meet the diverse needs of families. Examples include newsletters, web pages, library of resource materials, etc.
3. Family Support Provider Agencies shall assist families in accessing related supports (e.g., childcare and transportation) so that they may attend trainings and meetings.
4. Family Support Provider Agencies shall offer opportunities for families to brainstorm with other families regarding their needs for education and training. With individual and family input, Family Support Provider Agencies and the Department should offer or arrange training opportunities that enhance a family's ability to care for the family member with a disability and to advocate for needed supports.
5. Family Support Provider Agencies and DMR shall routinely circulate training brochures and information to individuals and families. Information shall be provided in the preferred languages of the families served or by way of other technologies to address sensory impairments and diverse learning styles. Subsidies, scholarships, and training opportunities may be arranged on a regional or collaborative basis in order to decrease associated costs.

C. FAMILY NETWORKING AND SUPPORT GROUPS

Family Support Provider Agency staff will assist families in finding or developing family resource or support groups, such as autism, sibling support, mother/father, and grandparent support. Family Support Provider Agency staff should facilitate opportunities for families to network both formally and informally. Families should be supported in sharing their expertise with other families and staff based on their interests and skills.

D. SUPPORTS AND SERVICES FOR COMMUNITY PARTICIPATION

Family Support Provider Agencies shall assist families in accessing generic or specialized supports to facilitate the inclusion of people with disabilities in community life. Family Support Provider Agencies and DMR shall promote the following:

- The use of the same community resources that are used by and available to other individuals and families;
- The full and active participation in the same community activities as individuals without disabilities who are living, learning, working, and enjoying life in regular contact with individuals without disabilities; and
- The development of friendships and relationships with individuals and families of their own choosing.

E. OUTREACH AND EDUCATION TO COMMUNITY MEMBERS AND ORGANIZATIONS

It is essential for Family Support Provider Agencies to have an active community education component to enhance access to generic resources and community life and to raise public awareness of the valued roles of people with disabilities and their families. Examples of community outreach and educational activities include presentations to community groups, newspaper articles, visits to local school classes, community forums, as well as informal use of “teachable moments” that arise in daily interactions with others. People with disabilities and their family members should be supported in providing community education themselves.

F. FLEXIBLE FUNDING OPTIONS

The Family Support Provider Agency shall provide an array of services to individuals and their families as described in these Guidelines & Procedures. There are two ways which individuals and families may utilize family support allocations. Some individuals or families may prefer to receive family support allocations directly in the form of a **stipend**. Others may prefer to have a Family Support Provider Agency pay for goods and services, including administrative costs, on their behalf. This option is referred to as a **direct provider agency payment**. These two options enable families to tailor their purchases and supports to best suit their needs.

These two options shall be discussed with the family during the family support planning process and families may select the option that they choose to utilize. Family Support Provider Agencies must advise families that depending on which of the funding allocation options is selected, the documentation requirements and contract language may differ.

- *Stipend* - Family Support Provider Agency makes a payment *directly to the individual or family*, who then *pays directly or is reimbursed* for the service or items.

- *Direct provider agency payments* - the Family Support Provider Agency employs the support staff person, contracts directly with that person, or pays for the service or items.

To request stipends or direct provider agency payments over \$1,800.00, an individual or family and the Family Support Provider Agency, shall submit a written request to the local DMR Area Director for prior approval.

1. Implementation of Stipend Option

If the family chooses to receive the allocation directly as a stipend, the following procedures shall apply:

- a) All individuals or families who exercise the stipend option for the first time must submit receipts or other agreed upon documentation to the Family Support Provider Agency for all purchases. These receipts must be submitted on a monthly basis for the first three months of the plan. Thereafter, the family, the Family Support Provider Agency and the DMR Area Office may agree to a less intensive documentation standard.
- b) At a minimum, the family must sign an expenditure summary every six months that catalogues the types and amount of expenditures they have made consistent with their Plan. See Attachment "A"
- c) Individuals and families will receive stipends as specified in their Family Support Plan, either on an as-needed or scheduled basis.
- d) Any item purchased with a stipend that costs in excess of \$500.00 must be registered with the Family Support Provider Agency. These items cannot be sold or given away. If a family no longer needs a particular item that was purchased with a stipend, it must be returned to the Family Support Provider Agency. After three years from the date of purchase, if it has not been returned to the Family Support Provider Agency the item becomes the property of the family.
- e) Family Support Provider Agencies shall bill expenditures made in the form of stipends to DMR as "stipends" on their contract submissions.

2. Implementation of Direct Provider Agency Payments on Behalf of a Family

If the individual or family chooses to have the Family Support Provider Agency purchase the item or pay for the service on their behalf, the following procedures apply:

- a) The individual or family shall acknowledge receipt of items purchased and services that were provided to them.
- b) The Family Support Provider Agency shall bill expenditures for such purchases/expenditures under the category that best represents the purpose of the expenditure. This may include staffing, sub-contract, capital purchase, or another category as appropriate under standard contracting regulations, but shall not be budgeted or billed as a "stipend".

As discussed above, stipends and direct provider agency payments are reported differently in contracts. This may require DMR contracts with Family Support Provider Agencies to be amended during the year, as the family's needs change.

3. Examples of Payment Options for Use of Flexible Funds

- a) **Equipment Purchase.** An individual or family wants to purchase an adapted bicycle as specified in their approved Plan.

Stipend Option. If the family selects the stipend option, the Family Support Provider Agency will give the individual or family the funds to make this purchase. The Family Support Provider Agency will then bill DMR for the stipend expenditure because the Commonwealth is paying the stipend and not purchasing the adapted bicycle. The individual or family who purchases the item is required to pay the appropriate sales tax because the family (not the Family Support Provider Agency) is buying the equipment. The individual or family will provide documentation of the purchase, such as a sales receipt, to the Family Support Provider Agency.

Direct Provider Agency Payment. If the family selects the direct provider agency payment option, the Family Support Provider Agency will purchase the adapted bicycle on behalf of the individual or family. The Family Support Provider Agency will pay the appropriate sales tax, if any is due. The bicycle is the property of the Family Support Provider Agency, not the family. The Family Support Provider Agency may bill DMR for the item as either “program support” or a “capital purchase,” depending on whether the cost was above the Family Support Provider Agency’s capitalization level. Standard contract rules apply to Inventorying and other administrative obligations.

- b) **Respite Services.** An individual or family wants to use their family support allocation for respite services at an agreed upon rate or amount as specified in their approved Plan.

Stipend Option. If the individual or family selects the stipend option, the Family Support Provider Agency will give the family the funds to purchase the respite service as identified in their Plan. The Family Support Provider Agency may provide the family with the stipend either before or after they have obtained the respite services in accordance with the family’s preference. The Family Support Provider Agency then bills DMR for the stipend expenditure. The individual or family shall provide the Family Support Provider Agency with documentation of payment of respite services.

Direct Provider Agency Payment. If the individual or family selects the direct provider agency payment option, the individual or family identifies whom they would like the Family Support Provider Agency to hire to provide respite services. The Family Support Provider Agency is responsible for any administrative and payment obligations. The individual or family does not need to document the expenditure, but must acknowledge receipt of the service to the Family Support Provider Agency. After confirming the family’s receipt of the service, the Family Support Provider Agency shall bill DMR for either “employee expense” or as a sub-contract, depending on the employment status of the respite staff.

Please note: In 1994, the Social Security Administration (SSA) ruled that family reimbursement (flexible support via reimbursement) and subsidy payments (stipends) provided under the state’s family support program were not counted as income by the Social Security Administration and, therefore, did not affect the receipt of social security program benefits with certain exceptions. For current and specific advice and information on the effect of the receipt of flexible support via reimbursement on any SSA program benefits, families and individuals are referred to the local Social Security Administration Office.

4. Implementation Procedures for Flexible Funding Options

The Family Support Provider Agency must have written procedures, approved by the DMR Area Director, which specifies documentation requirements for families for both the direct provider agency payment and stipend options. These procedures should meet the applicable audit standards of the Family Support Provider Agency and the Commonwealth. Minimally, the Family Support Provider Agency procedures shall address the following topics:

- Specific stipend and reimbursement options available to families.
- Information and/or training available to families regarding their reporting responsibilities to the Family Support Provider Agency, the Internal Revenue Service, and the Social Security Administration.
- Information regarding the development of Family Support Plans.
- Requirements regarding the submission of receipts for purchases to the Family Support Provider Agency.
- The requirements for prior approval of stipends or direct provider agency payments over \$1,800.00 by DMR Area Directors.

Please note, in situations when requests for stipends or direct provider agency payments are over \$5,000.00, an individual or family and the Family Support Provider Agency must submit a proposal and obtain approval in advance from the Area Director, Regional Director and Central Office.

IV. ALLOWABLE/ DISALLOWABLE EXPENDITURES

All family support is subject to appropriation, and all family support allocations are based upon existing resources. Family support allocations, whether direct provider agency payment or stipends, shall be used to supplement assistance available to the individual or family through generic funding sources, including other state or federal family assistance available to the family. DMR funds shall not supplant other available resources.

Following are examples of items for which family support allocations may be expended using either the stipend or direct provider agency payment option. The list below provides examples of items that may be appropriate expenses for payment with family support allocations. The list is not intended to be exhaustive, and families are encouraged to propose unique supports or options. Questions regarding appropriate expenditures for family support allocations should be referred to the DMR Regional Family Support Director for regional contracts and the Area Office Director for area office contracts.

A. ALLOWABLE EXPENSES

1. Respite Support

Respite is a service that provides temporary relief for families and caregivers. Respite care may be provided concurrently to other siblings if agreed to in advance by the Family Support Provider Agency, the family, and the respite worker. Respite can be provided in the individual's home or in a variety of out-of-home settings. It may be provided for varying lengths of time depending on the needs of the family and available resources. Respite reduces family/caregiver stress and thereby helps preserve the family unit, supports family stability, and prevents lengthy and costly out-of-home placements.

There are two forms of Respite Support: Family-Identified Respite and Provider-Identified Respite. The supports are the same, but the way in which they are paid and managed are different. The differences are as follows:

- a.) Family Identified Respite - respite supports provided by a person who is recruited, supervised, and paid by the family directly.
- b.) Provider Identified Respite - respite supports provided by a person who is recruited, trained, supervised, and paid by a Family Support Provider Agency.

2. Recreational/Social Activities

Activities or supports aimed at increasing/enhancing the social integration of the person with a disability; examples include fees for community recreation programs, scouting programs, etc. These supports may also contribute toward the cost of recreational opportunities for the family as a whole, such as family membership in the local YMCA, fees for family recreation, or assistance directly related to the increased cost of the individual to participate in a family vacation or other events, etc.

3. Child Care

After-school programs, child day care costs or a family's share of such costs for the individual or his or her siblings in order to allow the parent(s) to spend time alone with the individual or his/her siblings.

4. Home Management Support Services

Home management support services for assistance with chores, such as cooking, cleaning, and managing finances that enable the family to provide for the individual with a disability.

5. Short-Term Emergency Needs

Short-term (less than 3 months) or one-time expenditures that enable families and caregivers to continue to provide care for the individual with a disability. Examples of short-term emergency needs may include food, short-term rental assistance to prevent homelessness, clothing, car rental, or general household costs. Note: see note above on the effect of the use of such supports on the receipt of Social Security program benefits.

6. Specialized Diagnosis, Evaluation, and Treatment

Specialized diagnosis, evaluation, and treatment of the individual with a disability. Other examples include genetic counseling for the parents and siblings, costs for dental or medical care that are not covered by the family's insurance, and the cost of insurance premiums, etc. Costs associated with CommonHealth premiums are not allowable.

7. Specialized Equipment/Supplies

Personal equipment for the individual with a disability that is not covered by insurance, (e.g., positioning boards and special chairs, water or hospital beds, computers or communication boards, specialized household equipment such as an air conditioner or air purifiers, or home safety equipment such as an intercom for nap or night time monitoring). This also includes adaptive recreational or sports equipment that assists the individual to participate in community and family activities.

8. Specialized Nutrition and Clothing

Special diets or food, special clothing, or footwear. This also includes clothes that need to be replaced frequently due to the individual's special needs.

9. Specialized Utility Costs

Long-distance telephone calls to doctors and other resources, and supplemental heating and air conditioning costs related to the disability needs of the individual.

10. Therapeutic Services and Supports

Occupational, physical, speech, and behavior management therapies for the individual with a disability; other counseling and therapeutic services so long as the individual is not eligible for other funding sources for these services.

11. Transportation

Includes gas (or mileage), meals, and lodging related to the individual's special needs (e.g., medical appointments or hospital visits). Transportation costs normally associated with other DMR contracts are not allowable.

12. Vehicle Expenses

Family support allocations may be used to contribute toward the cost of vehicle modifications or the lease/purchase of a vehicle. The need for the vehicle or modification, lease or purchase must be specifically related to the functional limitation caused by the individual's disability. Any use of family support funds for vehicle expenses **must be submitted and approved in advance** following the process outlined below.

- a) The Family Support Provider Agency shall explore the possibility of modifying an existing vehicle owned by the individual or his or her family, before considering a proposal to use a family support allocation to contribute to the lease or purchase of a vehicle. Examples of modifications include, adding a van lift, ramp, tie-downs, or adaptive seating.
- b) The Family Support Provider Agency must explore and document the unavailability of alternative funding sources such as insurance, civic organizations, fund raising, and other generic resources before it submits a proposal for the use of a family support allocation for the modification or contribution to the lease/purchase of a vehicle.
- c) The Family Support Provider Agency proposal shall include the names and contributions of all generic funding sources that will be used in conjunction with Department resources.
- d) A decision flow chart that outlines the required process a Family Support Provider Agency and family must follow before submitting a proposal to the Area Director for use of a family support allocation for vehicle modification, lease or purchase is found in Attachment G.
- e) The following steps to request approval for funding must be followed.
 - 1- The Area Director of the local DMR Area Office must receive in advance for their review and recommendation the following information: a proposal detailing the request for funding; the individual's Family Support Plan that clearly defines and explains the need for a vehicle modification or contribution toward the lease/purchase of a vehicle; and the completed *Vehicle/Home Modification Funding Request Form* (Attachment F).
 - 2- If the Area Director approves the proposal and recommends funding, the request is forwarded to the Regional Director for his/her review, recommendation and signature.
 - 3- If the Regional Director approves the proposal and recommends funding, the request is forwarded to Central Office for final review and approval of funding.
 - 4- Once Central Office staff have made their final determination regarding the approval of funding, they will notify the respective Regional and Area

Director, and the Area Director will notify the family and the Family Support Provider Agency as to whether their funding request was approved or not.

- f) The funding for any approved vehicle modifications or contributions toward the lease or purchase of a vehicle must be paid through the stipend option.

Examples of vehicle modifications for which family support allocations may be approved, include:

- Van lift
- Tie downs
- Ramp
- Specialized seating equipment
- Seating/safety restraint
- Car payments (only on a one-time basis, and never to exceed 3 consecutive months)

Examples of vehicle modifications or lease or purchase for which family support allocations shall not be approved, include:

- The full cost of vehicle purchase
- Insurance costs
- Taxes

13. Home Modifications

Family support allocations may be used to contribute toward the cost of home adaptations that will directly benefit the individual with a disability and relate to his/her health and safety concerns. Any use of family support funds for home modification requests must be **submitted and approved in advance** following the process outlined below.

- a) The Family Support Provider Agency shall explore whenever possible, utilization of appropriate modifications that are portable to accommodate changes in residence, size of person, and changes in equipment and needs. In addition, all proposals for home modifications shall plan for the reuse of portable accommodations.
- b) The Family Support Provider Agency must explore and document alternative funding sources such as insurance carriers, civic organizations, and other state or federal funding resources before it submits a proposal for the use of a family support allocation for a home modification.
- c) The Family Support Provider Agency proposal shall include the names and contributions of all generic funding sources that will be used in conjunction with Department resources.
- d) Family support funding shall only be used for renovations that will allow the individual to remain in his/her home (primary residence), and must specifically relate to the functional limitation(s) caused by the individual's disability.
- e) A decision flow chart outlining a required process that a Family Support Provider Agency must follow before submitting a proposal for the use of a family support allocation for home modifications to the Area Director is located in Attachment H.
- f) The following steps to request approval for funding must be followed.
 - 1- The Area Director of the local DMR Area Office must receive in advance for their review and recommendation the following information: a proposal detailing the request for funding; the individual's Family Support Plan that clearly defines and explains the need for a home modification; and the completed *Vehicle/Home Modification Funding Request Form* (Attachment F).

- 2- If the Area Director approves the proposal and recommends funding, the request is forwarded to the Regional Director for his/her review, recommendation and signature.
 - 3- If the Regional Director approves the proposal and recommends funding, the request is forwarded to Central Office for final review and approval of funding.
 - 4- Once Central Office staff have made their final determination regarding the approval of funding, they will notify the respective Regional and Area Director, and the Area Director will notify the family and the Family Support Provider Agency as to whether their funding request was approved or not.
- g) The funding for any approved home modification must be paid through the stipend option. If a home modification request is approved, the family must submit, at a minimum, 3 bids that contain costs and a work agreement, to the Area Director and the Regional Family Support Director.

Examples of home modifications for which family support allocations may be approved:

- | | |
|-------------------------|----------------------|
| ➤ Ramps | ➤ Stair lift |
| ➤ Widening of doorways | ➤ Yard fence |
| ➤ Bathroom modification | ➤ Door alarm systems |

Examples of home modifications for which family support allocations shall not be approved:

- Modifications that have no direct impact on the functional limitations of the disability of the individual
- Additions to an existing home
- Remodeling solely for the purpose of increasing the value of the home

B. DISALLOWABLE EXPENSES

In addition to items that have been mentioned previously in these Guidelines & Procedures, Family Support Funds shall not be used for the following:

1. Items or activities that have limited benefit to the individual with a disability.
2. Any purpose that may directly or indirectly jeopardize the integrity of the program, for example, support for criminal conduct or any activity which places the individual at physical or medical risk.
3. The provision of services that are normally covered by other DMR service codes.
4. Purchasing of items or services that are not allowed by state regulation, including the regulations of the Division of Purchased Services regarding lobbying for litigation against the Commonwealth,
5. Purchase of items that are unreasonably expensive or extravagant.
6. Long-term assistance (greater than three months) in purchasing food and paying housing costs, such as rental assistance.
7. Paying for housing supports such as the principal on a mortgage, the down payment on a residence, or tax bills on property.
8. Costs associated with CommonHealth premiums.

Questions regarding the appropriateness of a proposed use of family support funding should be discussed with the individual's service coordinator and the involved Family Support Provider Agency. The Family Support Provider Agency shall confer with the Area Director or his/her designee, or the Regional Family Support Director based on contract assignment.

See 808 Code of Massachusetts's Regulations 1.00 et seq. (compliance, reporting and auditing for social and human services).

Utilization of family support funding to cover unapproved or disallowable expenses including those specified in these Guidelines & Procedures may jeopardize the continued participation by the family in the family support program.

V. FAMILY-GOVERNED, ENHANCED SERVICES & SPECIALTY PROJECTS

A. FAMILY-GOVERNED AND DIRECTED INITIATIVES

The Department has initiated family-governed and family-directed projects across the state. These projects enable families to exercise increasing control and influence over the direction and operation of these family support projects.

1. Family-Governed

Family-governed projects are hosted by a Family Support Provider Agency and in collaboration they work to ensure that all the Core Elements outlined in these Guidelines and Procedures are met.

In family-governed projects, families exercise control over major operational decisions including hiring/firing of staff, managing the budget, the development of policies and procedures, etc. Family governance also provides empowerment to family groups to determine their membership from an identified group of eligible, prioritized consumers and to establish a process to allocate family support funds to individual families. Individuals and families who choose to participate in a family-governed project bring with them their assigned family support resource allocation. Likewise, when individuals and families choose to leave a family-governed project, the amount of their family support resource allocation moves with them.

These projects require active support on the part of families, Family Support Provider Agencies, and DMR. The policies, rate of pay, and the form of evaluations that families decide on shall be consistent with these Guidelines and Procedures, DMR regulations, the Family Support Provider Agency's personnel policies, any related labor laws, and all other applicable laws and regulations.

There needs to be a clear understanding among all parties (i.e., the families, the Family Support Provider Agencies, and the Department) regarding the decisions which individuals and families will be empowered to make in family-governed projects. DMR Area Offices shall approve the amount of Departmental family support fiscal resources that it will dedicate to family-governed projects.

2. Family-Directed

Family-directed projects involve families in guiding the manner that supports are offered for each particular family support project. DMR and Family Support Provider Agency staff shall maintain governance of the project and will utilize the expertise of families to closely define project parameters. Final allocation and prioritization decisions remain with DMR and shall be made consistent with the DMR Mission Statement, these Guidelines & Procedures, the direct consultation of the involved families and all other applicable laws and regulations.

B. ENHANCED FAMILY SUPPORT SERVICES

Enhanced family support services provide more comprehensive and intensive services to respond to the unique, complex and multiple challenges of individuals and their families.

Intensive Flexible Family Support (IFFS) is a service provided in each of the DMR regions. It is time-limited (6-12 months), goal-oriented, and purchased as a discrete service. The primary goal of IFFS is to help maintain the integrity of families having one or more members with a disability who are experiencing severe stress, which is causing the child to be at risk of out-of-home placement. This service is available to families whose children are DMR eligible, between 3 and 18 years of age, and are living in the family home.

The Medically Fragile Family Partnership Program is a family-driven model of care and support that embraces the commitment of the Department to caring for children with significant cognitive, physical and complex health care needs who are living at home with their families. This service is provided in each of the DMR regions. This service provides comprehensive wrap-around supports to families who have children with complex, severe, health care and developmental needs. This service is available to families whose children are DMR eligible, between 3 and 18 years of age, and are living in the family home.

C. SPECIALTY FAMILY SUPPORT PROJECTS

In specific areas of the state the Department may offer unique projects or initiatives that respond to specific needs and/or interests of families, and are time-limited or targeted in nature. Examples of specialty projects include: Autism Support Centers, after-school programs, social/recreational programs, camps, Family Leadership Development, and planned facility-based respite programs.

VI. DETERMINING ELIGIBILITY FOR FAMILY SUPPORTS

A. ELIGIBILITY

In order to receive services and supports from the Department of Mental Retardation ("DMR" or the "Department"), including Family Supports, children and adults must be determined to be eligible in accordance with Department regulations. [See 115 CMR 2.01]. If an individual is determined eligible for DMR services, the Area Office may provide family supports dependent on availability of resources and prioritization.

Family support services shall be welcoming and easy to access. Staff members should assist families to understand how to complete the necessary steps to apply for DMR eligibility (e.g., whom to call, paperwork). DMR or the Family Support Provider Agency shall make interpreters and translated materials available in order to communicate effectively with families. Family privacy and confidentiality shall be respected at all times.

Eligibility for DMR services will be determined through a Regional Eligibility Team process. Applications for DMR services will be made available to families and individuals through the local DMR Area Offices, at local Family Support Provider Agencies, and in many other locations in communities that families would typically visit or use such as schools, health centers, hospitals, other state agencies, etc.

For children less than age 18, the Regional Eligibility Team will have 45 days from the date of application to review the eligibility assessment and issue an eligibility report. For individuals over the age of 18, the Regional Eligibility Team will have 90 days from the date of application to review the eligibility assessment and issue an eligibility report. Eligibility

assessments are generally completed on a first-come, first-served basis. Information regarding all children and adults who are found eligible for DMR services will be entered into the Consumer Registry System (CRS).

Family Support Provider Agencies will have no formal role in the application or intake process, but should assist families in submitting an application and providing assistance and support throughout the intake process as requested by families or by the Department.

If a DMR Area Director determines that services are needed on an emergency basis, the Area Director may make a preliminary decision regarding the applicant's potential for eligibility. If the preliminary determination is affirmative, the Area Director or his or her designee may request a Family Support Provider Agency to provide family support services necessary to avoid serious or imminent risk to the health or safety of the applicant or members of his or her family pending the eligibility determination. If an individual is later determined to be ineligible to receive DMR supports, DMR staff will assist the individual and his or her family to access other state-provided resources for which they may be eligible.

DMR will update these Guidelines & Procedures on an ongoing basis to reflect any changes in DMR eligibility criteria and process as developed. Application procedures and eligibility to receive DMR supports are governed by Department regulations; familiarity with these Guidelines & Procedures is not a substitute for a full review of those regulations. Additional guidance regarding the intake/application and eligibility process may be found in the Department's Eligibility Manual. In the event that any information contained in these Guidelines and Procedures or the Eligibility Manual conflicts with state or federal law or regulation, such law or regulation shall govern.

B. REDETERMINATION

1. Children

Children change a great deal as they develop, and the results of assessments performed during childhood may not be accurate or conclusive. The Department shall re-determine eligibility for DMR supports based on new and/or changing information or circumstances. The fact that the Department has determined a child eligible does not create a presumption that he or she will always meet DMR eligibility criteria. DMR may conduct a review of a child's eligibility on a periodic basis.

Children who have been determined to be eligible may be able to access DMR funded family supports subject to the availability of funding and prioritization.

2. Adults

DMR will conduct a formal eligibility determination of individuals when they turn 18 years old, including those currently receiving family supports, to determine whether they meet the adult DMR eligibility criteria. For those who meet the adult eligibility criteria, the transitional process into the adult service system will begin.

Individuals with developmental disabilities who have been determined to be eligible to receive family supports prior to age 18, but who do not meet the eligibility criteria for DMR adult services, shall not be able to access or purchase DMR funded adult services.

Individuals who meet the DMR adult eligibility criteria may be able to access needed adult supports, subject to appropriation, when they turn 22 years of age.

C. SERVICE COORDINATION

DMR provides service coordination for children and adults who are found eligible for DMR services. DMR will not provide lead service coordination for children and adults who meet another state agency's primary mandate. DMR staff will be sufficiently familiar with other human service agency mandates to refer individuals to the appropriate agency.

D. FAMILY CONTRIBUTIONS

Families are not required to contribute or provide financial resources in order to access family support services. Families may be asked to support family support programs by participating in activities to the extent they are able, (e.g., making voluntary donations or time commitments). Families shall be offered the opportunity to and be encouraged to participate by providing whatever form of service or assistance they can (e.g., serve on advisory boards or councils, provide transportation, provide supervision for activities, or provide support for other families). Some specific family-directed projects may require family participation.

E. CHILDREN AND ADULTS IN OUT-OF-HOME PLACEMENT

1. The respite and other support needs of families of children and adults with disabilities who live in out-of-home, 24-hour residential placements including residential schools, specialized home care, and foster care are the responsibility of the state agencies that fund those residential services. Agencies that provide such services include: Massachusetts Commission for the Blind (MCB); Department of Mental Health (DMH); Division of Medical Assistance (DMA); Department of Public Health (DPH); Department of Social Services (DSS); and Department of Youth Services (DYS).

In order for children in the legal custody of another state agency who reside in a foster care placement to receive DMR family supports, the child must be found eligible for DMR services, and the DSS/DYS foster care plan must state that a placement in a permanent home shall occur within the next six months.

2. In cases where a foster child is receiving DMR-funded family supports in a home in which other foster children reside, the presence of other foster care children in the home shall not result in an increased DMR funded family support allocation. The foster care subsidy should be sufficient to meet the needs of the children in foster care. DMR family support resources shall not be used to supplement services to children who are in the care and custody of another state agency. Family Support Provider Agency staff who find themselves in the position of supervising children who are not subjects of the DMR Family Support Plan but who reside in a common home should bring this situation to the attention of the appropriate DMR contract manager. If a Family Support Plan that offers adequate safeguards for the individual and support staff cannot be developed, provision of DMR family supports may be withdrawn.

F. OTHER STATE RESOURCES

1. DMR does not provide primary supports to individuals from birth to age 21. Specifically, DMR does NOT provide funding for out of home placements such as residential schools, community group homes, and foster care, etc. for individuals less than 22 years of age. After an individual turns 22, residential supports may be provided, subject to available resources and prioritization.

2. Children from birth to three years old with developmental disabilities are entitled to services through the Department of Public Health (Public Law 99-457) and are not eligible for services through the Department of Mental Retardation.
3. Primary supports for individuals 3 to 22 years of age are provided under an educational entitlement, the Individuals with Disabilities Education Act (IDEA) at the federal level and Chapter 766 at the state level. DMR supports complement the educational services that the child and family receive in their home and community. In such cases, the local school district is responsible for conducting assessments that should provide information needed to determine whether the child might be eligible for DMR family supports. A child is entitled to the initial evaluation free of cost from the school district. DMR does **NOT** provide educational funding or cost share mandated entitled services such as transportation, extended day services, or residential placements.
4. The developmental, diagnostic and social needs of a child may qualify that child for other state agency support. Other state agencies that may provide support resources include: Massachusetts Commission for the Blind (MCB); Department of Mental Health (DMH); Division of Medical Assistance (DMA); Department of Public Health (DPH); Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH); Office of Child Care Services (OCCS); Department of Social Services (DSS), and Department of Youth Services (DYS). The DMR service coordinator will work collaboratively with other key agency staff to ensure the coordinated delivery of services.
5. Adults may qualify for multiple adult state agency services. Other state agencies that may provide support resources include: Massachusetts Rehabilitation Commission (MRC); Division of Medical Assistance (DMA); Office of Elder Affairs (OEA); Department of Mental Health (DMH); Department of Transitional Assistance (DTA); Department of Public Health (DPH); Massachusetts Commission for the Blind (MCB); and Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH), etc. The DMR service coordinator will work collaboratively with other key agency staff to ensure the coordinated delivery of services.

VII. PRIORITIZATION, ALLOCATION OF RESOURCES, AND APPLICANT TRACKING PROCESS

A. PRIORITIZATION

1. DMR shall use the factors set forth in the Determination of Level of Support Needs: Family Support Allocation Guidelines (Attachment B) to assist it to prioritize individuals based on their need for family support. These factors shall be reviewed at least annually. Factors for determining priority to receive Family Supports shall include, but are not limited to:
 - Characteristics of the individual with a developmental disability;
 - Characteristics of the primary caregiver;
 - Other unique circumstances; and
 - Family strengths and other available supports.
2. For children, the Area Director shall assign priority for services or supports based on the severity of the child's need:

FIRST PRIORITY: Provision, purchase, or arrangement of the requested service(s) or support(s) is necessary to meet one or more of the child's disability-related needs which are not within the purview of another state or local agency and which, if not met, are likely to result in a serious or immediate threat of harm to the child or another;

SECOND PRIORITY: Provision, purchase or arrangement of the requested service(s) or support(s) is necessary to meet the needs of the child or his or her family member and is not the responsibility of another state agency and is not otherwise available;

THIRD PRIORITY: Provision, purchase or arrangement of the requested service(s) or support(s) will enhance the family's capacity to meet the needs of its members, or will facilitate or promote the inclusion of the child in community life;

FOURTH PRIORITY: The child is eligible for DMR supports but is currently eligible for or in the care or custody of, under the supervision of, or receiving 24-hour residential services from another state agency or entity.

3. For adults, the Area Director shall assign priority for services or supports based on the severity of the individual's need.

B. ALLOCATIONS

The amounts of family support allocations provided/made available to individuals and families by DMR are based on a standardized needs assessment, the priority assigned to an individual by the Area Director, and the availability of resources.

For allocations related to family-directed or governed projects refer to Section V.

C. THE MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER PROGRAM

In some instances, individuals with developmental disabilities who receive family supports may be eligible for participation in the Medicaid Home and Community-Based Services (HCBS) Waiver Program ("Waiver Program") that is administered by DMR. For further information on the Waiver Program, families or individuals should contact the DMR service coordinator.

D. TRACKING OF DMR ELIGIBLE INDIVIDUALS AND FAMILIES

1. Area offices shall maintain contact with the families of DMR eligible individuals who have requested family support services.
2. Area Office personnel should:
 - assist individuals in accessing DMR services, if available;
 - inform families of appropriate volunteer and generic organizations and other state agency resources;
 - inform families of educational opportunities, support groups, and other resources available through Family Support Provider Agencies;
 - introduce families to other family-to-family networks and connections;
 - ensure that appropriate governmental agencies are aware of the needs of both families who are receiving family supports from DMR and those who have applied for but are not yet receiving services.

E. FAMILIES SUPPORTED BY MORE THAN ONE AGENCY

1. In general, individuals and families should receive DMR family support coordinated by only one Family Support Provider Agency (FSPA). Exceptions might include situations where an individual requires specialized services or supports provided by another Family Support Provider Agency, or a family's stated preference to have ongoing contacts with more than one Family Support Provider Agency.
2. If a family is receiving supports from more than one Family Support Provider Agency, then the Family Support Provider Agency staff, the family and DMR Area Office staff shall select a single "family support provider agency" to coordinate requests for or provision of services (e.g., consolidate resources under one FSPA, decrease allocation to one provider, or in exceptional cases, maintain the current FSPA contracts).
3. Family Support Provider Agencies shall provide written notice to a family and to the appropriate DMR Area Office staff regarding any proposed changes to a family's family support allocation or its role in coordinating/arranging services for the family. The family shall have the opportunity to discuss such changes with the Family Support Provider Agency prior to their implementation.

F. TRANSFER OF FAMILY SUPPORT FUNDING TO ANOTHER DMR REGION OR AREA

1. The DMR Area Director is responsible for ensuring continuity of service to families. There shall be no disruption of support when families transfer from one area or region to another. The DMR Area Director or designee shall initiate the Transfer of Family Support Funds as indicated in the following process.
2. To complete a change in "area of meaningful tie," the following steps should be taken:
 - The DMR service coordinator (SC) from the originating Area Office should contact the SC from the destination Area Office and provided him or her with information regarding the individual and his or her pending transfer.
 - The Area Director from the originating Area Office has transferred DMR family support funds to the destination Area Office.
 - The originating Area Office must complete a "Change in Meaningful Tie" form and a "Transfer of Family Support Funds" form (Attachment C) and forward them to the destination Area Office. If this transfer of funds is occurring across DMR Regions, then the "Inter-Regional Transfer Request" form must also be completed and sent to the Budget Director in Central Office.
 - The originating Area Office must send a letter notifying the family that there will be a change in the area of meaningful tie (Attachment D). The originating Area Office has updated the Consumer Registry System (CRS) data regarding the individual.
3. DMR Area Offices shall adhere to the following guidelines regarding fund transfers. The following factors shall be implemented in the process:

Family Support Allocations:

- The Area Office from which a family originates shall transfer the amount of their family support to the destination Area Office.
- Allocation transfers shall occur at the end of fiscal year in which the change of meaningful tie took place unless otherwise negotiated by the respective Area Directors.
- In general, the originating Area Office shall transfer the amount of the family's allocation to their destination Area Office. NOTE: If the rate for supports in the destination Area Office is not equivalent to the rate in the origination Area, the purchasing power may be different.

- The destination Area Office shall provide the transferred level of family support funding for a minimum of twelve (12) months following the completion of the formal change of meaningful tie.
- After the twelve month period following the formal change of meaningful tie, the destination Area Office may evaluate the individual's/family's needs and make an adjustment in the level of the family support allocation. In the event that the family support allocation is reduced, the balance of the original family support allocation shall not be returned to the originating Area or Regional Office.
- The involved Regional and Area Directors shall determine the amounts of intensive flexible funds to be transferred on a case-by-case basis.
- "One-time" allocations shall not be transferred.

Family Directed/Governed councils shall adhere to the above-stated policy regarding the transfer of family allocations.

VIII. DEVELOPMENT OF FAMILY SUPPORT PLAN

A. OVERVIEW OF FAMILY SUPPORT PLANNING

1. The Family Support Provider Agency shall support each individual and his/her family to develop a **Family Support Plan** ("Plan") who is found eligible for DMR services in accordance with DMR regulations and is identified to receive services as part of the specified FSPA contract capacity. Family Support Plans are **not required** for those families who are **only** receiving Information and Referral or only on an agency mailing list to receive newsletters, training information, etc.
2. During the planning process, it is important to identify the natural supports that the individual and family currently have and the needs that such supports satisfy/meet. If a natural support does not fully meet an identified need, other types of supports should be considered.
3. Whenever possible, the Family Support Provider Agency shall assist the family in exploring the availability of generic resources that will help to meet their needs.
4. When an individual reaches the age of majority (18 years), whenever possible, the supports offered should lead to increased independence for the individual and be consumer directed. The individual's competence and guardianship status shall be considered during support planning.

B. THE FAMILY SUPPORT PLAN

1. The Family Support Provider Agency shall develop a Family Support Plan in accordance with the requirements outlined in Attachment A. This should include:
 - a) Supports, goods, and services the family is currently receiving from DMR and other public and private sources, including the amount and cost of these services. (See Attachment A for a Family Support Plan).
 - b) Other supports, goods, and services that are identified as needed by the family, including the estimated costs to obtain such services.
 - c) The Plan, signed by at least one family member/guardian, the individual when appropriate, and the Family Support Provider Agency staff, must be completed and forwarded to the DMR Area Office for review.
2. The Family Support Provider Agency shall provide the families with a copy of their Plan in their primary language.
3. For new families the Plan must be developed and forwarded to the DMR Area Office within 30 days of the initial referral. For families who have been receiving family support services these plans must be reviewed and updated annually by the family and FSPA, and then forwarded to the local DMR Area Office within 60 days of the new fiscal year.
4. The Plan shall be modified when the needs of individuals, families, or resources change significantly. Families have the option of moving their own family support allocation to a family support provider agency of their choosing that is under contract with DMR. The DMR Area Director or designee shall approve modified Plans, prior to their implementation.
5. In cases where proposed Plans include billable costs to DMR that exceed \$1,800.00, the Family Support Provider Agency must obtain written approval from the DMR Area Director or his or her designee prior to implementing the Plan.
6. In situations in which an adult is living at home with his/her family and receiving family supports, the Family Support Plan should be incorporated into, or at a minimum, attached to the adult's Individual Support Plan.

C. FAMILY SUPPORT AND ADULT TRANSITION PLANNING

1. The Department recognizes that as part of the transition planning process that occurs when educational entitlements will be ending, the individual and his or her family may make an informed decision to have the individual leave the family home and move to a more independent living situation.

Families, who have been receiving family support for one year or more, may use their family support allocation to fund a portion of the individual's transition to independent living. Only the family's current year allocation shall be available for this purpose.

2. In cases where family support allocations are used to support an individual's transition to independent living, the DMR Area Office shall restore DMR's family support base resources for the following fiscal year.

D. FAMILY SUPPORT PLANS AND BROKERAGE

Individuals and families may wish to utilize a broker to assist them in identifying, planning, accessing, and evaluating services and supports. The broker's role as the family's agent is to support the individual's and family's choices and to participate in planning by identifying generic and other resources that address their choices. An individual and /or family may obtain brokerage services through a Family Support Provider Agency that offers those services, or the individual/family may utilize their family support allocation to hire a broker directly.

IX. ADMINISTRATIVE RESPONSIBILITIES OF FAMILY SUPPORT PROVIDER AGENCIES

A. RESOURCES

1. Each Family Support Provider Agency shall provide sufficient staffing resources to meet their contractual requirements and their responsibilities set forth as core elements in Section II.
2. Family Support Provider Agencies are expected to provide sound administration of the program:
 - Fiscal management and invoice preparation
 - Submission of required DMR reports
 - Clerical and other necessary support
 - Ancillary service functions
3. Each Family Support Provider Agency shall identify a staff member to act as its family support coordinator to provide oversight and direction for the program.
4. Family Support Provider Agencies shall provide opportunities for families to participate in the hiring, supervision, and evaluation of family support staff.
5. Family Support Provider Agencies shall have staff that reflect the cultural and linguistic diversity of the community.
6. Family Support Provider Agencies shall have a written emergency plan that is developed in conjunction with, and approved by, the DMR Area Office. The scope of the response system will be dependent on the needs of families served by the Family Support Provider Agency and the breadth and types of supports provided.

B. TRAINING

1. General Requirements
 - a) Each Family Support Provider Agency is responsible for orienting all employees to the Agency's philosophy, goals, organizational structure, services, benefits, policies and procedures, and to the specific responsibilities of the employee's job.
 - b) Family Support Provider Agencies shall provide training to ensure that family support staff and respite providers are qualified to provide the type of care required for each individual. Additional specialized training for the specific needs of an individual shall be provided as necessary. In cases that a respite provider is a family unit, all family members who are going to assist the individual must receive training specific to the

individual. Families of the individual must be included in developing and, when appropriate, in providing training programs.

- c) Each Family Support Provider Agency will provide or arrange for relevant training for its staff. Agencies are required to maintain written documentation of training it provides including schedules and attendance records.
- d) Agencies shall have written policies on file for waiving pre-service or in-service training for any family support staff or respite providers who have completed equivalent training, or who meet the required level of training as demonstrated by equivalent qualifications, or experience.

2. Pre-Service Training

- a) Sufficient training and evaluation of each employee must take place to ensure that he or she is competent to provide services to an individual before the employee provides support to a family. This requirement may be met by a demonstration by the employee of knowledge and competence acquired through comparable training and/or experience.
- b) Pre-service training topics shall include, at least, the following:
 - i. Values and Principles of Family Support
 - Family Partnerships
 - Family and individual empowerment
 - Community inclusion
 - Human rights
 - Confidentiality
 - Cultural diversity and sensitivity
 - ii. Health and Safety
 - Emergency procedures, including reporting of abuse
 - Basic first aid, including CPR
 - Seizures (basic information)
 - Fire safety (basic information) and reporting/responding to other natural disasters
 - Universal precautions
 - iii. Orientation to agency and individuals with disabilities
 - Overview of DMR and other human service agencies
 - Crisis management procedures
 - Policies, procedures, paperwork
 - Specifics on the individual(s) to be supported

3. In-Service Training

- a) Family support staff and respite providers shall receive the ongoing training necessary to provide quality support to the individuals and families they serve.
- b) Training shall be provided or arranged to meet the specialized needs of the family member with a disability or to enhance the professional/personal development of the Family Support Provider Agency staff.
- c) Family input regarding training needs should be solicited on a regular basis and at least annually.

- d) Family Support Provider Agencies need to recognize the strengths and skills of the families they support, and encourage the participation of family members as trainers.
- e) Documentation of attendance at in-service training or training waivers for those showing competence in a given skill area shall be kept on file at the Family Support Provider Agency.

C. AGENCY-PAID STAFF

Individuals who are hired by and on the FSPA payroll to provide support services shall meet the following requirements. This includes individuals who are referred by the family to provide support services but are hired and paid by the FSPA.

1. Age
The minimum age for a staff person employed by a Family Support Provider Agency who is working directly with individuals and their families is 18.
2. Qualifications
Applicants must possess appropriate qualifications to serve as family support staff as evidenced by interviews, two personal and/ or professional references and a Criminal Offense Records Inquiry (CORI) check.
3. Communication
Staff members shall have the ability to communicate effectively in the language and communication style of the individual to whom they provide services and his or her family.
4. Site
The Family Support Provider Agency whose staff routinely provide any services in their own homes is responsible to determine that the homes are free from physical, fire, and other safety hazards. CORI checks shall be completed on all people over 18 years of age living in the household if supports are provided in the home. The FSPA shall retain documentation of home inspections and CORI check on file.

D. FAMILY-PAID STAFF

The Department supports the practice of using family-paid support workers. If a family selects this option, the Family Support Provider Agency is exempt from and will not perform certain administrative requirements such as reviewing respite provider qualifications, providing training, conducting home inspections, and developing disaster plans. Families shall sign a waiver indicating that the FSPA advised them regarding its exemption from specific requirements if the family chooses to hire its own staff and the family's responsibility to meet the requirements. The FSPA must maintain in the file written acknowledgement of the families' knowledge of the FSPA's exemption from the required activities identified in the list above.

1. The following family members cannot be reimbursed for providing family support: parents, children, or spouse of the individual with a disability.
2. Family Support Provider Agencies shall inform families about their administrative responsibilities (e.g., Social Security Tax payments and deductions, Income Tax deductions, Unemployment Tax, workers' compensation) if they choose to use family

members or support workers who are not affiliated with the FSP Agency. This may be accomplished through seminars, interviews, or printed materials.

3. A family may spend some of its Family Support allocation to obtain liability or worker's compensation insurance.
4. Issues of liability, tax responsibilities, and compliance with the Fair Labor Standards Act are complex. Family Support Provider Agencies are not required to provide specific tax or legal advice to families, but may provide information or, may provide advice if they have first obtained qualified professional advice, and assume responsibility for advice they issue. Family Support Provider Agency staff may assist families in accessing professionals such as accountants or attorneys who can provide them with appropriate guidance.

E. RECORDKEEPING

1. The Family Support Provider Agency shall maintain a written record for each individual and family receiving family support services. Each record shall include at a minimum:
 - a) Documentation of DMR eligibility and referral for family support services;
 - b) A copy of the Family Support Plan;
 - c) A copy of the ISP, if any;
 - d) Name, address, and telephone number of people to contact in case of emergency (in a readily accessible place);
 - e) A picture of the individual;
 - f) All pertinent correspondence;
 - g) Records of critical incidents;
 - h) Records of service and supports delivered in sufficient detail to allow for accurate billing and monitoring of the appropriateness of the expenditure;
 - i) Relevant home studies for provider homes; and
 - j) A record of special medical/health needs of the individual, if any.
2. Family Support Provider Agencies will submit the following to DMR:
 - a) Family Support Plans, annually, and any updates or revisions;
 - b) Summary of the annual evaluation of consumer/family satisfaction, including a plan to respond to identified concerns and recommendations;
 - c) Summary of family allocation and utilization reports;
 - d) Required billing and service delivery reports (monthly); and
 - e) Performance Outcome Measures (six month updates).
 - f) Other reports related to need or service activities as requested by the Department.

F. COMPLAINT RESOLUTION

Each Family Support Provider Agency shall have a written complaint resolution process available to individuals and families concerning service allocations and other matters. Determinations made pursuant to such process are subject to review by DMR. Each Family Support Provider Agency shall do the following:

- Inform families regarding the complaint resolution protocol
- Provide families with a copy of the process, upon request
- Advise families and individuals of their right to have decisions reviewed by the DMR Area or Regional Office staff and provide relevant contact information.

With regard to decisions concerning eligibility for DMR supports, individual's appeal rights are set forth in DMR regulations.

G. FAMILY PARTICIPATION, FAMILY-DIRECTED/FAMILY-GOVERNED INITIATIVES

Minimally, each Family Support Provider Agency must have a Family Advisory Council, consisting of a majority of family members. The Council will advise the FSPA regarding the planning, implementation, and evaluations of services and supports.

In some areas, the Department and Family Support Provider Agencies will create opportunities for family-governed and family-directed projects. Families in these projects will assume some of the administrative responsibilities of the Family Support Provider Agency, as agreed to by the families, the Family Support Provider Agency, and the Department.

X. GOALS AND PERFORMANCE OBJECTIVES

DMR and Family Support Provider Agencies shall maintain management practices that ensure compliance with all applicable laws and regulation, state audit procedures and contractual obligations. Standard performance outcome measures for Family Support are located in Attachment E. All DMR Regional and Area Offices shall use these standard measures annually to evaluate Family Support Provider Agencies.

XI. EVALUATIONS

Opportunities for family input and involvement shall be extended to every family who receives services. All individuals and families served by the Family Support Provider Agency shall have the opportunity at least annually to evaluate programs, voice their opinion regarding family support services, identify unmet needs, and suggest new approaches for supporting families.

Family Support Provider Agencies shall share the results of the annual evaluation process with all families and submit a written copy of the summary to the DMR Regional and Area Offices prior to the start of each fiscal year. This summary shall document the number of families who participated in the evaluation process and include a plan of action, jointly developed with families, that responds to concerns and identified needs.

XII. Attachment A

FAMILY SUPPORT PLAN

Family Name: _____
 Individual's Name: _____
 Address: _____

Year of Plan: _____
 Date of Birth: _____
 SS#: _____

COMPELLING ISSUES FOR THIS FAMILY

SUPPORT SERVICES CURRENTLY RECEIVING

Service Type	Agency	Amount of Hours / Dollars

GOODS & SERVICES IDENTIFIED AS NEEDED BY FAMILY

Service Type	Proposed Provider		

FAMILY STRENGTHS / ASSETS

Family Member: _____
 Agency Staff: _____
 Area Director (or designee): _____

Date: _____
 Date: _____
 Date: _____

Attachment B

FAMILY SUPPORT ALLOCATION GUIDELINES

The following factors shall be considered in determining the level of supports needed by an individual and family and the effect these factors have on a family's ability to function effectively. Review of these guidelines will assist the Department in determining the priority of needs for supports and services.

CHARACTERISTICS OF THE INDIVIDUAL WITH A DEVELOPMENTAL DISABILITY

Behavioral Challenges

Does meeting his/her behavior needs cause significant stress for the family?

Does the individual require constant supervision?

Is the behavioral difficulty sporadic or is it a routine occurrence?

Physical Challenges

Does the individual have a physical disability (e.g., vision, speech, hearing, etc.) that requires additional time and support in caring for him/her?

Does the individual have difficulty expressing his/her basic needs?

Ambulation

Does the individual have difficulty with walking that requires physical assistance? Or use of adaptive equipment (e.g., walker, cane, etc.)?

Does the individual need to use a wheelchair?

Self-Help Skills

Does the individual need physical assistance with activities of daily living (e.g., bathing, eating, dressing, toileting, etc.)?

Is this assistance considered extraordinary relative to the individual's age?

Does the individual require lifting in order to transfer to a bed, toilet, bathtub, etc?

Medical Challenges

Is there more than routine medical care involved in supporting the individual?

Is there a significant medical condition present?

Does the individual have seizures?

Is specialized medical equipment (e.g., G-tube) required on a routine basis?

CHARACTERISTICS OF THE PRIMARY CAREGIVER

Physical/Health Concerns of Primary Caregiver(s)

Is there any health-related issue that causes significant difficulties for the family?

Does the age of the caregiver(s) pose an additional stress factor?

Single/Working Parents

Does the status of the primary caregiver's employment create additional stress for the family?

Other Individuals at Home Requiring Supervision

Are there other individuals with a disability at home who require support and supervision?

Other Multiple Family Problems

Are there other factors at home that cause additional stresses on the family's ability to effectively meet family responsibilities?

Does the primary caregiver need assistance with parenting skills?

Is there a risk of out-of-home placement?

OTHER UNIQUE CIRCUMSTANCES

Recent Stressful Event

Has the family experienced a recent event or episode that has increased the level of stress (e.g., death, illness, divorce, etc.)?

Language/Cultural Barrier

Does the family's primary language or cultural customs limit its access to existing services?

FAMILY STRENGTHS AND OTHER AVAILABLE SUPPORTS

Family Members

Do other family members support the primary caregiver in taking care of the individual?

Friends and Community

Do friends and neighbors lend assistance or support to the primary caregiver?

Is there access to church or civic organizations?

Insurance Benefits

Does the individual or family qualify for insurance benefits or other entitlements that offer support services?

Community/Other Agency Services

Does the family receive other community or agency services that relieve the family from day to day care or provide other family supports?

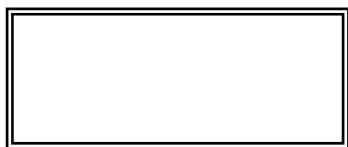
Day or School Program

Is the individual involved in a day, work, or school program on a daily basis?

LEVEL OF INTENSITY OF SUPPORT NEEDS

____ Intermittent
____ Limited

____ Extensive
____ Pervasive



TRANSFER OF DMR FAMILY SUPPORT FUNDING

TO: (DESTINATION AREA DIRECTOR)

FROM: (ORIGINATING AREA DIRECTOR)

DATE:

NAME:

DOB:

SOCIAL SECURITY #:

CLASS MEMBER STATUS (specify):

ORIGINATING AREA:

DESTINATION AREA:

DATE OF TRANSFER:

AMOUNT TO BE TRANSFERRED:

PROVIDER:(If Identified)

**CC: CONTRACTS MANAGER
REGIONAL DIRECTOR**

Attachment D

DATE

Dear _____:

Your recent move to a new community shall necessitate a change in the responsible local Department of Mental Retardation Area Office.

As of ____/____/____, potential supports for your family shall be coordinated by _____ from the _____
(Name)
Office, _____,
_____.
(Address) (Phone)

This representative, who is knowledgeable about the types of supports offered in your new community, shall be contacting you to welcome you and to learn more about your support needs.

Sincerely,

Area Director

cc: Receiving Area Office
Regional Family Support Director

Attachment E

FY _____ Contractor Name: _____ Amendment #, If Applicable: _____ If
Federal Funds, CFDA #: _____
(for internal DMR use) within FY amendment #: _____

ATTACHMENT 2: PERFORMANCE MEASURES

For use with Department of Mental Retardation Family Support Services (Program Code 3176)
--

Program Name:	Document ID #:	MMARS Code:	Program Type:	UFR Program #:

1. Providers offer all families the opportunity to participate in family directed organizational activities and promote the empowerment and leadership development of families.

Indicators:

- A. ☒ 100% of families are offered opportunities to participate in family directed activities

- B. ☒ 100% of families are given the option to direct their own fiscal allocation, within the New Family Support Guidelines & Procedures _____
- C. ☐ Percent of families who take advantage of the option to direct their own fiscal allocation # _____

- D. ☐ Families participate on a family council, advisory or governing board # _____
Specify _____
- E. ☐ Families are supported in participating in Family Leadership Training

Specify _____
- F. ☐ Families participate in policy development, program planning and implementation, evaluation, and program revision # _____

- G. ☐ Families participate on hiring committees for program staff # _____
Specify _____
- H. ☐ Specific examples for Intensive Flexible Family Supports (IFFS), Medically Fragile or Specialty Projects: Specify _____

Comments/Action Steps:

2. Providers are responsive to the specific ethnic, cultural, and linguistic needs of families relative to the demographics of the geographic area they serve.

Indicators:

- A. ☐ Program brochures and related information are consistently available in different languages {Specify languages: _____
_____}
- B. ☐ Providers engage in activities that promote outreach to families of diverse backgrounds.
Examples _____

- C. ☐ Culturally competent interpreters are available as needed.
Examples
- D. ☐ Bi-lingual staff are recruited and hired. # Specify strategies
- E. ☐ Partnerships are developed with multi-cultural community organizations. #
Specify
- F. ☐ Specific services, are provided or arranged, based on identified needs, such as, support groups for Latino or Vietnamese families.
Specify
- G. ☐ Families from diverse racial and cultural backgrounds participate in trainings, family-directed projects, and all other family directed organizational activities as identified in Outcome Measure 1.
#
- H. ☐ In-service training is provided for staff to help develop cultural competence and understanding of disability across different cultures.
Specify
- I. ☐ Specific examples for Intensive Flexible Family Supports (IFFS), Medically Fragile, or Specialty Projects. Specify
Comments/Action Steps:

3. Providers offer timely, relevant information to families about community resources and other pertinent services, develop partnerships with other community organizations, and provide or arrange a range of support services to meet the needs of families.

Indicators:

- A. ☐ Agency provides written materials such as newsletters, web pages, library of reading and resource materials, etc. that meets the literacy needs of families.
Specify
- B. ☐ Families have access and related resources (i.e., transportation, child care) to attend available trainings: e.g., special education, behavioral supports, futures planning and transition, estate planning, etc. Specify # of trainings offered; Number of people who attended;
 Provide examples of trainings offered and by whom
- C. ☐ Families have opportunities to participate in related support groups such as autism, sibling support, fathers' support groups, etc.
Specify groups and #s
- D. ☐ Provider develops partnerships with other community organizations, (elder services, housing departments, churches, temples, etc.), and local school systems to provide support, resources and to build capacity for inclusion of individuals and families; Specify
- E. ☐ Individuals and their families are supported to access inclusive community based activities, e.g., membership at the YMCA.
Specify
- F. ☐ Specific examples for Intensive Flexible Family Supports (IFFS), Medically Fragile, and/or other Specialty Projects:
Specify
- Comments/Action Steps:

4. Providers engage individuals and their families in a meaningful planning process and develop an individualized plan for the provision of family support services with each family.

Indicators:

- A. ☒ Family Support Expenditure Plans are developed with all families receiving services { 100%}
- B. ☒ Family support plans are in compliance with the New Family Support Guidelines & Procedures, and if applicable, meet other DMR requirements {100%}
- C. ☒ Family support plans identify the strengths of families and document other potential resources available to meet the needs of families { 100%}
- D. ☐ Family support plans reflect the dynamic and changing needs of individuals and their families, relative to their respective stages of life.
Specify
- E. ☐ Specific examples for Intensive Flexible Family Supports (IFFS), Medically Fragile, and/or other Specialty Projects:
Specify
- ☐

Comments/Action Steps:

5. **Providers give families the opportunity to express satisfaction/dissatisfaction with services provided, solicit ideas to improve services and develop and implement jointly with families a plan of action to respond to the concerns and needs identified.**

Indicators:

- A. ☒ At least on an annual basis, families are given the opportunity and encouragement to give feedback about services through a variety of means including consumer satisfaction surveys, family forums, or other program evaluation tools {100%}
- B. ☐ Families are involved in the development of the satisfaction survey tool and approaches
#
- ☐
- C. ☐ Families are provided with an annual summary of this feedback { Copy of report}
- D. ☐ Families are involved in the development of a plan of action which responds to the needs and concerns identified, and this plan is made available to families { Copy of plan}
- E. ☐ Families have an easy way to raise concerns about specific program operations or staff and are informed about this process
Specify
- ☐
- F. ☐ This annual satisfaction survey/process includes questions that assess the extent to which families feel welcomed and listened to, have control in the planning and selection of services, find it easy to get information, are treated with respect when they need to provide information about their family, and are satisfied with the timeliness and quality of services {Copy of survey questions}
- G. ☐ Specific examples for Intensive Flexible Family Supports (IFFS), Medically Fragile, and/or other Specialty Projects:
Specify
-

Comments/Action Steps:

6. **Providers meet administrative and fiscal requirements, and ensure that adequate services and flexible resources are non-intrusive and cost-effective. When vendors provide staff they must ensure they are qualified, trained personnel to meet the needs of the individual with a disability and their family.**

Indicators:

- A. ☒ Contract expenditures are maintained within the allocated budget
Specify
- ☐ Provider adheres to the New Family Support Guidelines & Procedures
Specify
- ☐
- B. ☒ Provider complies with the requirements for allocation of family support stipends
Specify
- ☐

- C. ☒ *Provider submits all required reports/documentation on time*
Specify
- D. ☐ *Provider recruits sufficient, qualified, personnel and offers or arranges necessary training and supervision*
Specify
- E. ☐ *Specific examples for Intensive Flexible Family Supports (IFFS), Medically Fragile, and/or other Specialty Projects:*
Specify
- Comments/Action Steps:

Attachment F VEHICLE OR HOME MODIFICATION FUNDING REQUEST FORM

This form must be completed when making a request to utilize family support dollars for any of the following; Vehicle modification, lease, purchase, or home modification. This form, the Family Support Plan, and the funding proposal should be submitted in advance to the Area Office Director for review and recommendation.

Name of Individual: _____ Date of Birth: _____

Area Office: _____ Service Coordinator: _____

Family Support Provider Agency: _____ Person Completing Form: _____

What is the request for? Vehicle _____ Home _____

Total purchase price/modification cost: _____ Requested amount of DMR funds: _____

Does the request relate directly to the functional needs of the individual? Yes _____ No _____

Please describe: _____

Have other funding resources been explored and documented? Yes _____ No _____

Is this request the most cost-effective option? Yes _____ No _____

Please Identify and Explain _____

Area Director Review and Recommendation: Yes _____ No _____

Area Director signature and date: _____

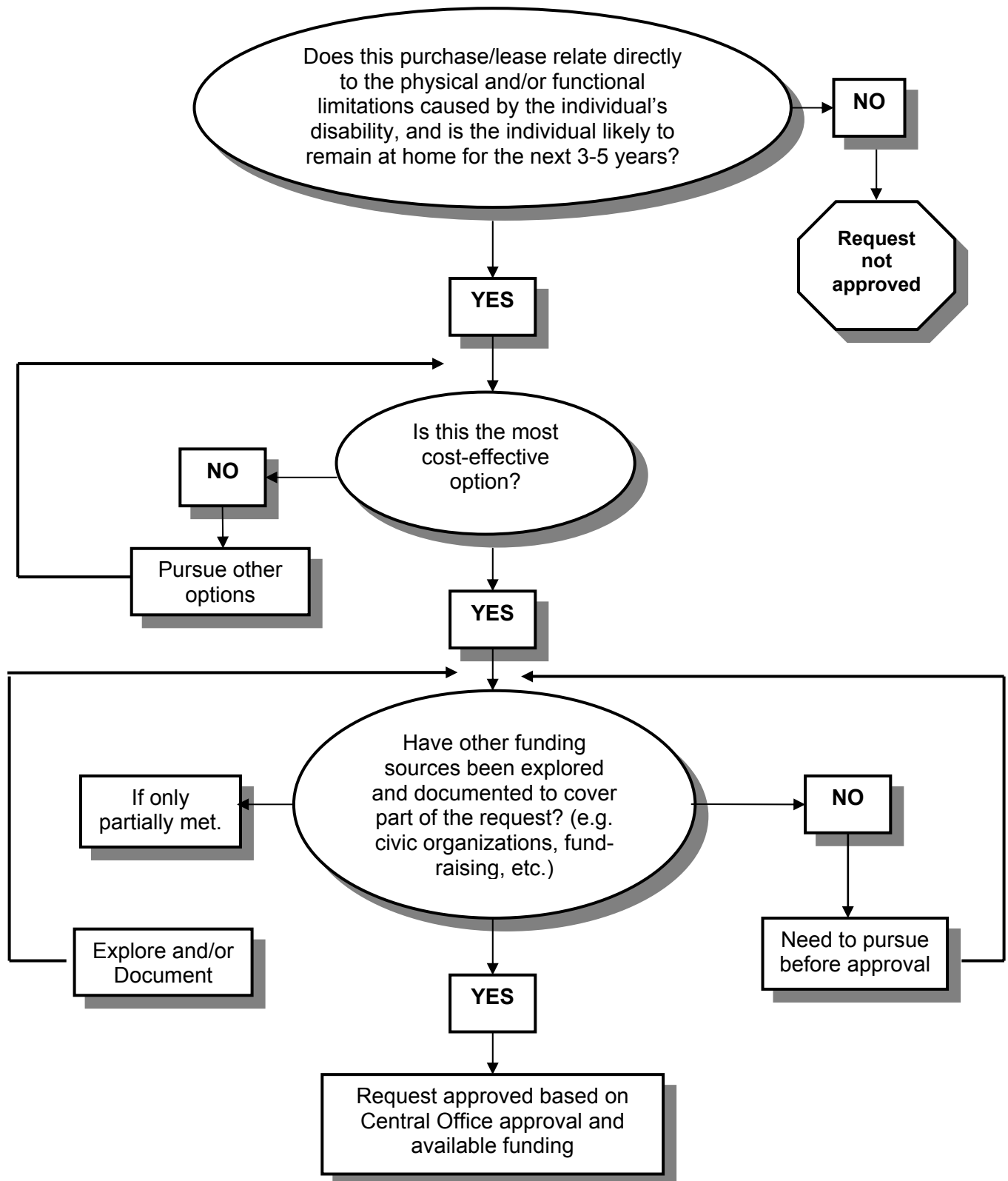
Regional Director Review and Recommendation: Yes _____ No _____

Regional Director signature and date: _____

Central Office Review and Approval: Yes _____ No _____

Signature and Date: _____

Attachment G
VEHICLE MODIFICATION OR LEASE/PURCHASE GUIDANCE



Attachment H HOME MODIFICATION GUIDANCE

